

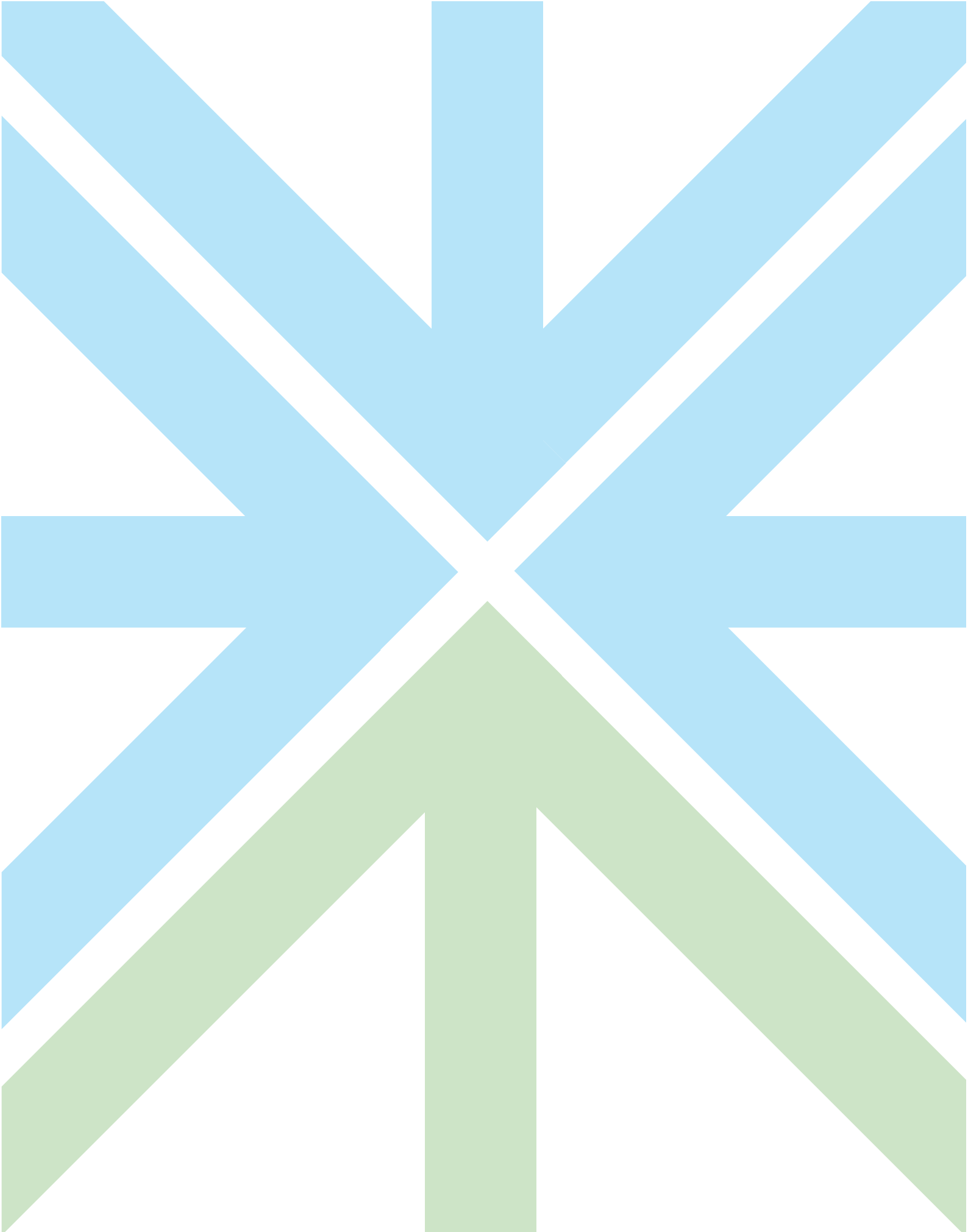


The Human Rights of People Living with Dementia: from Rhetoric to Reality



A Dementia Alliance International publication
to coincide with the adoption by Alzheimer's Disease International
of a Human Rights based approach,
and to coincide with Dementia Awareness Week UK 2016

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WELCOME TO HUMAN RIGHTS FOR PEOPLE LIVING WITH DEMENTIA

We are launching this landmark Dementia Alliance International (DAI) booklet because, as a direct result of DAI's advocacy, a rights-based approach including access to the United Nations Convention on the Rights of Persons with Disabilities (CRPD), that we have advocated for, has just been adopted by Alzheimer's Disease International.

This is a watershed moment for people with dementia across the world.

The human rights of people with dementia lie at the heart of our work. Access to the UN Disability Convention was one of the demands made by DAI's Chair, CEO and Co-founder, Kate Swaffer at the World Health Organisation's First Ministerial Conference on Dementia held in Geneva in March 2015. Since then, we have done everything we can to make a reality of that demand.

DAI's three key demands at the WHO First Ministerial Conference in Dementia in 2015.

- We have human right to a more ethical pathway of care, including our pre and post diagnostic care, including rehabilitation.
- Being treated with the same human rights as everyone else, under the Disability Discrimination Acts and UN Convention on the Rights of Persons with Disabilities
- That research focuses on care as much as a cure.

What matters to us now is that people living with dementia will be empowered to use their undisputed right of access to this and to other relevant UN Human Rights Conventions, including a future Convention on the Rights of Older Persons.

DAI is now much better placed to support national Alzheimer's Associations and other organisations for people with dementia in making full use of CRPD in ways outlined at the Budapest conference by Professor Peter Mittler in his role as DAI Human Rights Adviser.

At the request of ADI, we are also preparing a document for the Boards of all National Alzheimer's Associations or Societies, which will suggest ways in which their work can be more firmly based on human rights principles in general and on the Disability Convention in particular.

This booklet provides a basic introduction to Human-Rights Based Approaches (HBRAs) – a UN approved system, which has been applied across all sectors. We think this is a good tool to enable national Alzheimer Societies to use these approaches in their relationships people with people living with dementia, within their own organisation and in their own country, as well as with governments, professional organisations and above all with the media and the general public.

Adopting PANEL principles is an excellent first step, but it is not a substitute for CRPD because it lacks an accountability system by the people it is designed to benefit. For this reason, most of this booklet focuses on ways in which the Convention can be used to promote the well-being and quality of life of people living with dementia.

We know from experience that it will take time and a re-evaluation of values and priorities at all levels to make it possible for people with dementia to benefit from this resolution. But after years of advocating for the rights for people with dementia and their significant others, we are now on our way.

This publication has been written and published on behalf of Dementia Alliance International with the support of numerous professionals in the field and in particular our Human Rights Advisor, Professor Peter Mittler.

Best wishes,



Kate Swaffer
Chair, CEO, Co-founder
Dementia Alliance International



WHO ARE WE?

Dementia Alliance International (DAI) is a worldwide, non-profit, association of people with dementia at all ages. It aims to represent, support, and educate people living with all forms of dementia and provides a unified voice of advocacy, empowerment and support to their individual autonomy and an improved quality of life.

Dementia Alliance International is the peak body globally for people living with a dementia and the global voice of people with dementia.

DAI is an independent self-advocacy organisation of people with dementia, in partnership with Alzheimer's Disease International and whenever mutual collaboration is possible, with all national Alzheimer's organisations.

It is important to note here that DAI is not competing in any way with other advocacy organisations but rather contributing a unique voice, unique services and a focused advocacy and support service specifically of, by and for people with dementia.

Membership is free and open to anyone with a medically confirmed diagnosis of any type of dementia (www.joinandai.org).



Chris Roberts from the UK wearing a Dementia Alliance International member t-shirt

WHAT THIS GUIDE IS ABOUT

The purpose of this guide is to say why we believe rights are so important in protecting the interests of people living with a dementia all around the world. ADI's groundbreaking commitment to a human rights policy, which includes CRPD, could be a game-changer for people with dementia and for national Alzheimer Associations.

They will need to develop a partnership of the kind that DAI enjoys with ADI in which both work together but each respects the autonomy of the other. Just as DAI is the voice of people with dementia, ADI is the voice *for* people with dementia.

This guide is primarily for people who have been given a diagnosis of dementia. Feel free to share it with your significant others, including friends and family members, supporters and anyone who might advocate on your behalf. You might draw strength from campaigning with others if you live with dementia, and can do that globally by joining Dementia Alliance International (www.joindai.org) and also by joining your local Alzheimer's organisation. This booklet may also be useful to other organisations concerned with issues relating to dementia and rights, as well as volunteers and professionals in the dementia field.



DAI members at the Alzheimer's Disease International 2016 Conference in Budapest: (L-R) Dennis Frost, Helga Rohra, Agnes Houston MBE, Hilary Doxford, Mary Radnofsky, Kate Swaffer, Peter Mittler CBE, Chris Roberts

WHAT ARE RIGHTS?

A right gives you authority to speak for yourself and to join with others whose rights are not respected or abused. Many books and scholarly papers have been written about human rights, including an increasing number about the rights of people with disabilities but it is only very recently that the rights of people with dementia have begun to be considered. For example, the UK Mental Health Foundation recently published a report on the rights of people with dementia that has stimulated both discussion and criticism (Mental Health Foundation 2015).

More to the point, there are now several books by people living with dementia which reflect a strong commitment to advocacy for the human rights of people with dementia world-wide (Swaffer 2016; Bryden 2015; Taylor 2009; Whitman 2015; Rohra In press). DAI is asking national Alzheimer's organisation Board Members to read and discuss these books when considering ways in which their societies can become a more human rights based organisation, as well as in their work with governments and the biomedical and social science research community. At least one of these books should be read and discussed when decisions are being made about any matter affecting people with dementia. *Nothing About Us Without Us*; *No more Us and Them*. This is our right.

The 1948 UN Universal Declaration of Human Rights protects every citizen in the world, including people with dementia who live with disabilities due to their diagnosis of dementia. Later UN Conventions focused on the rights of people who have failed to benefit - women, children, ethnic and religious minorities. Other Conventions concerned with fundamental human rights include the Convention on Cultural, Social and Economic Rights which is particularly relevant to people living with dementia. Discussions are under way about a possible Convention on the Rights of Older Persons. ADI and DAI are in touch with the relevant UN bodies, as well as with National Human Rights Institutions (NHRIs) that provide independent advice to Civil Society Organisations such as Disabled Persons Organisations in most countries.

This booklet introduces you to examples of these rights. It is written not only to inform you about your rights but to highlight ways in you can join forces with others to claim them locally, nationally and internationally. DAI is here to provide information, encouragement and support.

WHY ARE RIGHTS IMPORTANT?

Rights are not just legal. Long before changes to the law in South Africa, there was a moral consensus that no one should be subject to discrimination on the basis of the colour of their skin. The disability movement, which began in the 1960s, saw itself as part of the civil rights movement for racial and gender equality. Rights for people with dementia are no different.



Professor Peter Mittler CBE presents on human rights at ADI2016

USING A HUMAN-RIGHTS BASED APPROACH

Since 2003, the United Nations has been developing a Human-Rights Approach (HBRA) across the whole of its work. The basic rationale for this is [The Human Rights Based Approach to Development Cooperation: Towards a Common Understanding Among UN Agencies](#).

Detailed guidelines and toolkits are available for organisations interested in this approach. The best introduction to HBRA in relation to both disability and dementia comes from the [Scottish Human Rights Commission](#).

This reflects the leadership, which Scotland has provided since 2009 when the Scottish Parliament adopted a Charter of Rights for People with Dementia in Scotland based on the PANEL Principles:

PARTICIPATION in decisions, which affect their human rights

ACCOUNTABILITY of those responsible for the respect, protection and fulfillment of human rights

NON-DISCRIMINATION AND EQUALITY

EMPOWERMENT to know their rights and how to claim them

LEGALITY in all decisions through an explicit link with human rights legal standards in all processes and outcome measurements

The Scottish government adopted PANEL principles when the UK government ratified the UN Convention on the Rights of Persons with Disabilities in 2009.

Scotland is the first country to have included people with dementia in its implementation of this Convention and to have appointed a Scottish Dementia Working Group in 2002 of people with dementia, which advises the government, with the support of Alzheimer's Scotland.

A European Working Group of People with Dementia advises Alzheimer-Europe; its chair, Helga Rohra, is a Board Member, and there are five¹ other national or regional Dementia Working Groups globally like this. We also strongly believe it is imperative that committees or groups of people with dementia are given appropriate disability support to enable them to take part in decision-making and to advise the work of every national Alzheimer Society or Association.

We believe that the work of these groups will be enhanced greatly through strong collaboration with Dementia Alliance International because of the global work we are doing. It is through collaboration, and working together, that all people with dementia, all advocacy organisations and governments will have the best chance of creating real change for people with dementia. Reducing the stigma and discrimination, is important to everyone, just as our access to civil society at every level is a human right.



1. Scotland Dementia Working Group 2002
2. European Dementia Working Group 2012
3. Alzheimer's Australia Dementia Advisory Committee 2013
4. Irish Dementia Working Group 2013
5. Japan Dementia Working Group 2014
6. Ontario Dementia Working Group 2014 (regional)
7. Kiama Dementia Advisory Group 2014 (regional)

¹ England and Wales are currently working towards a Dementia Working Group.

UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The UN Convention on the Rights of Persons with Disabilities was adopted in 2006 but is only now beginning to be used by the dementia community. Its ratification by the European Union and 163 countries commits their governments in international law to implement each of its General Obligations, General Principles and 37 substantive Articles.

Amongst the many differences between the CRPD and earlier UN Conventions is that it is the first to include representatives of potential beneficiaries as equal partners with governments in negotiating each of its Principles and Articles. It is also a landmark in the history of the disability movement because international Disabled Persons Organisations (DPOs) representing different constituencies have succeeded in working together as a coalition, despite differences in policies and priorities.

People with dementia are included in the definition of CRPD in Article 1:

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.”

The all-important General Principles of the Convention are reflected in each of its main Articles.

GENERAL PRINCIPLES

- Respect for dignity, autonomy, freedom to make choices, independence
- Non-discrimination (disability, gender, ethnicity, age)
- Full participation and inclusion in society
- Respect for difference; acceptance of disability as part of human diversity
- Equality of opportunity
- Accessibility
- Equality between men and women

ARTICLES

The Articles provides detailed guidance on the relevance of these principles to important areas of everyday life on the same basis as others.

These include:

- Right to Life
- Accessibility at all levels
- Equal Recognition Before the Law
- Freedom from torture, cruel, inhuman or degrading treatment, exploitation, violence and abuse
- Living independently and participation in the community;
- Respect for home and family
- Health
- Rehabilitation
- Employment
- Adequate standard of living and social protection
- Participation in political and public life, cultural life, recreation, leisure and sport



DAI Board member, Agnes Houston MBE from Scotland

HOW CAN ALZHEIMER'S ASSOCIATIONS OR SOCIETIES AND SELF-ADVOCACY ORGANISATIONS USE THE CONVENTION?

- Lobbying and advocacy to ensure that regional, national and local dementia policies and future plans reflect CRPD Principles and Articles.

None of the new Dementia Strategies recently launched within the framework of the Global Alzheimer's and Dementia Action Alliance (GADAA) which was set up by ADI and other NGO's reflect CRPD Principles and Articles, although nearly all countries are committed to CRPD through ratification. On the other hand, WHO's own Disability Action Plan for 2014-2022 was co-written with a consortium of Disability NGOs and has clearly used CRPD to create that policy.

DAI is now raising this issue with WHO which has provided exemplary leadership in both disability and dementia – but from different sections. We are now asking them to express that leadership by reminding governments that their ratification of CRPD includes people with dementia and their care partners.

- Insisting on the right of people with dementia to participate as equals in the development of policy and in the implementation of the CRPD. Had they done so, the discrimination described above might have been prevented.
- Using their right to submit parallel reports when their country is reporting to the CRPD Committee.

DAI and ADI are in contact with Alzheimer's Canada to offer support for such an opportunity this year and there is a strong possibility that other countries will do so in 2017.

- Holding their governments to account

Each of the 163 governments that have ratified CRPD must submit a detailed report on implementing each of its General Principles and Articles to the CRPD Committee after two years and then every four years. 17 of its 18 members are persons with disabilities from different countries.

You can meet them one to one on this 7-minute [YouTube: Celebrating 10 years of the CRPD](#). Watch out for Diane Kingston on the committee who has gone out of her way to support DAI and therefore all people with dementia.

- Publicising the CRPD Committee's Concluding Observations to advocate for implementation of their recommendations, using the press and social media if necessary. All the relevant information is on [United Nations Human Rights: Committee on the Rights of Persons with Disabilities webpage](#).

CONCLUSIONS

People with dementia began advocating for a human rights based approach many years ago, and through consistent advocacy for our more basic human rights, starting with inclusion at events, conferences and in groups discussing policy and strategies that concern them. Our long-standing demand for “Nothing About Us Without Us” is now beginning to be met, and we believe things are starting to change.

We wish to acknowledge the support of Alzheimer’s Disease International, and their Chair Mr. Glenn Rees AM and Executive Director Mr. Marc Wortmann, for their willingness to collaborate with us and support our work and our rights.

Pioneers such as the late Peter Ashley, Christine Bryden and the late Dr Richard Taylor, and the members of the first advocacy group, Dementia Advocacy and Support Network International (DASNI) started the movement in 2000. Since then we launched as an exclusive group of, by and for people with dementia on 1st January 2014, DAI has been working tirelessly to continue this work, and to ensure that the rights of all people with dementia will be met. This includes greatly improved diagnosis, care and disability support, and inclusion in everything that is about us.

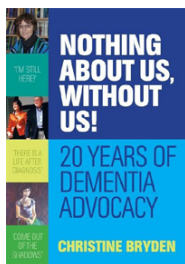
DAI advocated strongly for the inclusion of a person with dementia to join the World Dementia Council in 2014, and since that time, two people with dementia are now members, including DAI’s Chair, CEO and co-founder and Hilary Doxford, also a member of the European Dementia Working Group. Since that time, we have placed human rights onto the global stage and are now working with other organisations towards this.

This booklet is the first of many, to support individuals and organisation working towards a human rights based approach for people with dementia, so that together, we can ensure it will happen.

Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it’s the only thing that ever has.

(Margaret Meade)

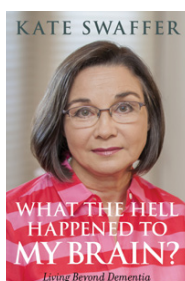
BOOKS BY PEOPLE LIVING WITH DEMENTIA



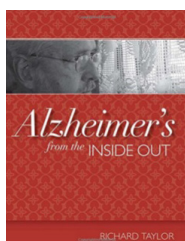
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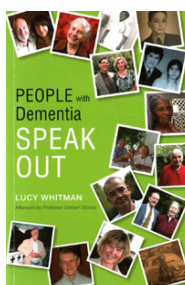
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